

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Washington – State Sponsored Endowed Trust Fund

Issue: Financial Security for People with Developmental Disabilities

Summary

The State of Washington developed a program to assist families in creating a trust fund for people with developmental disabilities. The program provides a way for families to put aside resources for the future needs of their family member with a disability without jeopardizing the person's eligibility for other basic benefits, such as Medicaid and Social Security. The state set aside a \$5 million endowment to offer a 25 percent match to private contributions made to a trust fund. Eighty-two people have enrolled in the program's first six months.

Introduction

People with developmental disabilities have needs that last a lifetime. Some families set up trust funds to ensure their family member with a developmental disability has available resources after parents or other caretakers are not available. Unlike a traditional savings account, these trust funds are not counted as part of the persons' income and provide a safeguard to their rights to benefits such as Medicaid and Social Security.

However, most trust funds for people with disabilities involve fees that many families cannot afford. The State of Washington offers an affordable program that encourages families to set up a trust fund for their family member with a developmental disability. People with developmental disabilities may also set up trusts on their own behalf.

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This report briefly describes the Washington State Developmental Disabilities Endowment Trust Fund. This document is based on interviews with the state agency staff at the Developmental Disabilities Endowment Trust Fund, housed within the Washington State Department of Community, Trade and Economic Development, and representatives of the Arc of Washington who manage the individual trust accounts.

Background

The Washington State Developmental Disabilities Trust Fund has been in the making since 1999, beginning with an idea from a state senator and members of grassroots advocacy groups for people with disabilities. Together, they envisioned a trust fund program that would offer a stable resource to support people with developmental disabilities throughout their lifetime. Members of these advocacy groups lobbied the state legislature to draw attention to the issue, and the legislature established a \$5 million endowment to assist families in setting up individual trust accounts.

After the passage of the legislation, the state chose the Arc of Washington to manage the funds. Because the Arc of Washington has supported programs for people with developmental disabilities since 1936, the Arc brings a high degree of credibility and visibility to the endowment program.

Intervention

The trust fund provides state matching funds to families' contributions to a trust fund. Families must contribute for three years to qualify for the matching funds, which are 25 percent of the family's contributions. People can receive a maximum of \$775 in state matching funds per person per year, and a lifetime limit of \$7,750 in state funds. The minimum monthly contribution is \$25, and there is no limit on personal or family contributions.

The fund requires initial and annual fees for program expenses, including bookkeeping, tax preparation, outreach, enrollment, and program coordination. The fees are matched with state funds, however, to minimize the trust fund's cost to families. For example, the \$600 enrollment fee is matched from the endowment into the person's trust fund automatically upon enrollment, so there is no net cost for enrollment. In addition, the endowment matches part of the annual management fees and all of the tax preparation fees through June 30, 2007.

An up-front enrollment fee can be a barrier to some families, but program staff said the \$600 enrollment fee is less than or comparable to most other attorney or enrollment fees required to create a trust fund account. Also, families who cannot afford the \$600 enrollment fee can place their name on a list to reserve matching funds for a period of two years, which allows time for families to save the \$600 fee.

The \$5 million endowment is invested along with Washington State's other \$54 billion in assets. As a result, the endowment is part of a larger pool of monies that program staff believes have a good return potential with relatively low risk. The rate of return since July 2000 has been 5.4 percent.

Anyone who meets the definition of a person with a developmental disability in state law can benefit from the program. Individuals interested in this program must first submit an enrollment form found on the Arc of Washington web site. The Arc then reviews the documents and contacts applicants to assist them in the

enrollment process. The endowment trust fund can be used for a myriad of purposes that are not included in the services offered or

The endowment is invested with Washington State's other assets.

funded by public programs, within the guidelines of the fund's governing board. Possible uses for the trust fund include education, training opportunities, supported living services, shopping, advocacy, and legal services.

In addition to obtaining information directly from the Arc website, people can learn of the program through channels such as newsletters, parents'

coalitions, the statewide fathers' network, and local media coverage. The state has also

Many fees are matched by state endowment funds to minimize the cost to families.

compiled a mailing list of potential enrollees over the course of the two years and has promoted the

program through presentations at various public events.

Implementation

After the creation of the endowment, the governor appointed a seven-person governing board to manage the fund. Board members are knowledgeable in business, public policy, finance, or law and are responsible for establishing the policies to administer the endowment fund. Four of the seven board members are parents of adults with developmental disabilities.

In planning for the Endowment Trust Fund, the staff of Washington's Department of Community, Trade and Economic Development sought expert advice from attorneys, actuaries, managers of pooled trusts, and people with developmental disabilities and their families. For two years, members of the governing board considered this information when developing the program's details. The governing board developed an investment strategy, analyzed the tax implications, wrote the policies and rules, completed an actuarial analysis, and designed both a fee structure and the trust documents.

On behalf of the governing board, Washington state then solicited contractors to conduct outreach, manage the individual trust accounts, and provide bookkeeping for the individual accounts. Merina & Company, a certified public accounting firm, was selected to provide bookkeeping for the individual accounts, and to prepare the tax reports. The Arc of Washington was selected for outreach, enrollment and disbursement management. The contractors work closely with the state staff and the governing board to ensure that all of the new systems are well coordinated and are operating smoothly. The high level of credibility of these contractors has enhanced the attractiveness of the program.

The governing board intends to seek additional funding sources for the matching funds, such as local foundations, to continue offering these funds after the \$5 million in state funds have been allocated.

Impact

Program staff described the initial interest in the program as encouraging. In the first six months since enrollment began in June 2002, 82 families have enrolled.

Discussion Question:

How could a state measure the impact of a trust fund on savings for people with developmental disabilities?

Contact Information

For more information about the Washington State Developmental Disabilities Endowment Trust Fund, please contact Jeanne Marie Thomas, Department of Community, Trade and Economic Development, at (800) 680-8034. Online information about the Washington State Developmental Disabilities Endowment Trust Fund is available at www.arcwa.org/endowmenttrust.htm.

This report is one of a series of reports by Medstat for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series will be available online at CMS' web site, <http://www.cms.hhs.gov>. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.